Support available for people experiencing memory difficulties or dementia in Sunderland

### Issue 1 – Published April 2025





The information in this booklet has been taken from 'Support available for people experiencing memory difficulties or dementia in Sunderland' which has information on a range of subjects which you may also find useful.

Find the full document at: www.healthwatchsunderland.com

Scan for the latest edition of this booklet





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The information in this booklet is a section that has been taken from the full booklet titled, 'Support available for people experiencing memory difficulties or dementia in Sunderland'. The full booklet has information on a range of subjects which you may also find useful.

Healthwatch Sunderland regularly updates these booklets. The copy you have may not be the latest version. For the most current copies of all the associated booklets, please visit: www.healthwatchsunderland.com or call us on 0191 514 7145.

If you have information to add or notice anything outdated in the booklets, please contact us and these will be considered.

### Contents

### **About Healthwatch Sunderland**

# Healthwatch Sunderland is your local health and social care champion.

We make sure NHS leaders and social care decision makers hear your voice and use your feedback to improve care. We can also help you to find reliable and trustworthy information and advice.

It is our vision to live in a world where we can all get the health and care we need.

It is our mission to make sure people's experiences help make health and care better.

#### Our values are to:

- Listen to people and making sure their voices are heard.
- Include everyone in the conversation especially those who don't always have their voice heard.
- Analyse different people's experiences to learn how to improve care.
- Act on feedback and driving change.
- **Partner** with care providers, Government, and the voluntary sector serving as the public's independent advocate.

### Why we did this work

During our engagement with the Essence Service, which supports people in the early stages of dementia and their carers, we heard from local carers about some of their experiences. They expressed concerns about the lack of information available on local support services following their family members' diagnoses. Many felt unsure about where to go for help and were not aware of the available resources. This feedback was also recognised by the Essence Service during their feedback sessions held in Dementia Action Week 2023.

In response to this need, we collaborated with the Essence Service, carers and other local partners to create a booklet named 'Support available for people experiencing memory difficulties or dementia in Sunderland'. This document offers key support information on a range of subjects. This may be useful for people experiencing memory difficulties and those living with dementia. The information in this booklet, 'Finances', has been taken from the full booklet.

Please be aware that some of the services mentioned, are only available to people with a dementia diagnosis.

#### Non means tested benefits

People of state pensionable age may be entitled to attendance



allowance (please see page 6). People under state pensionable age, may be entitled to personal independence payment. Once you get either attendance allowance or personal independence payment, you may be entitled to a discount of council tax based on your mental impairment.

#### Get help and advice

There are support organisations across Sunderland that can help with free information, advice and guidance on welfare support, debt, employment, and housing matters plus help with food (such as local food banks). Please see the table below:

| Area   | Locations  | Support Service   |
|--|--|---|
|  | Copt Hill, Hetton,   | Shiney Advice and Resource Project (ShARP)  |
|  | Houghton, Shiney Row   | Call: 0191 385 6687<br>Email: <u>advice@shineyadvice.org.uk</u>                               |
| East Doxford, Hendon,<br>Millfield, Ryhope,<br>St Michael's.         | Citizens Advice Sunderland   |   |
|  |  | Call: 0808 278 7950<br>Email: <u>enquiries@citizensadvicesunderland.co.uk</u>                 |
| North Castle, Fulwell,<br>Southwick, St P                            | Castle, Fulwell, Redhill,  | Sunderland West Advice Project (SWAP)   |
|  | Southwick, St Peters   | Call: 0191 5142930<br>Email: <u>swap@pallionactiongroup.co.uk</u>                             |
|  | Washington Central<br>Washington East<br>Washington North<br>Washington South<br>Washington West | Shiney Advice and Resource Project (ShARP)  |
|  |  | Call: 0191 385 6687<br>Email: <u>advice@shineyadvice.org.uk</u>                               |
| West Barnes, Pallion, Sandhil<br>Silksworth, St Anne's,<br>St Chad's | Barnes, Pallion, Sandhill,   | Sunderland West Advice Project (SWAP)   |
|  |  | Call: 0191 5142930  |
|  |  | Email: <a href="mailto:swap@pallionactiongroup.co.uk">swap@pallionactiongroup.co.uk</a>       |
| City wide  | All areas of Sunderland,<br>including Washington<br>and the Coalfields                           | Essence Service Information and Advice<br>Service for people registered with their<br>service |
|  |  | Call: 0191 522 1310   |
| includ   | All areas of Sunderland,<br>including Washington<br>and the Coalfields                           | <b>Age UK Sunderland Front Door Service</b><br>Available for people aged 50+                  |
|  |  | Call: 0191 565 9045   |

This page has been written by a local gentleman with lived experience of caring for a loved one with dementia. You will note Age UK factsheets are often mentioned throughout this booklet. The gentleman found these a valuable guide of information for him.



#### "They are well written, accurate, easy to read, and are kept up to date. They are available online or in a booklet."

#### Attendance allowance

Anyone with a dementia diagnosis, over the state pension age can apply for attendance allowance. It is a benefit which is not means-tested and is not taxable. People who need help with daily living, including personal care, day or night because of physical or mental disability i.e. dementia can apply for the benefit. To qualify, the disability must have lasted for at least 6 months. You can spend the allowance how you choose.

It is best to make the claim as early as possible. The allowance can not be backdated. Currently, there are two weekly rates of benefit. The lower rate at £73.90 and the higher rate at £110.40. The higher rate is for those who need care day and night. Benefits are paid every 4 weeks.

If the person receiving the benefit is admitted into hospital the benefit will stop after 28 days. If the person receiving the benefit goes into a care home that is funded in total or partly by the local authority, then the benefit will stop after 28 days. The Department of Work and Pensions must be informed.

#### Personal Independence Payment

If you are under the state pension age, you might want to think about applying for personal independence payment.

#### Pension credit - extra money if you are on a low income

Pension credit is a means tested benefit for older people. This means that what you get depends on your income and your savings.

#### More money in your pocket

Age UK have written a useful guide which explains the different benefits that are available and how to claim them.



#### Call: 0191 514 1131

Email: enquiries@ageuksunderland.org.uk Website: www.ageuk.org.uk/sunderland and search 'information and advice' (and scroll

down to free booklets and online information).

Or for personalised support contact Age UK Sunderland's Essence Service, Sunderland's Dementia Hub on: 0191 522 1310.

The finance section was written in April 2025. If you notice anything which needs updating, please contact Healthwatch Sunderland on 0191 514 7145

### Finances



#### Council tax reduction

If a person has a dementia diagnosis they are exempt from paying council tax. To qualify the person must receive certain benefits, below are some examples:

- Incapacity benefit
- Attendance allowance
- · Personal independence payment
- Disability Living allowance.

If other adults live with someone who has a dementia diagnosis, they may get a 25% discount off their bill, if only one person is counted for Council Tax. This will be from the date of the diagnosis.

If the person with dementia goes into residential care, it is important to let the council know, as the discount will no longer apply. However, if the spouse or partner remains as the only adult living at the property, they can still claim a 25% discount.

If you provide care for someone who lives with you or if you are a resident care worker, you may also qualify for a 25% discount.

For more information contact Sunderland City Council: Call: 01919 520 5551 Website: www.sunderland.gov.uk (search 'severely mentally impaired').

#### Private pensions/annuities

If the person with dementia has a private, personal or occupation pension or a private annuity, and they are married or in a civil partnership, they can 'gift' 50% of the pension to their partner who lives at home.

Social services will not include this amount when doing their financial assessment. (For more information about this and other financial matters, see Age UK factsheet number 39.)

For more information about this: Call: 0191 514 1131 Email: enquiries@ageuksunderland.org.uk Website: www.ageuk.org.uk/sunderland (search 'information and advice' and scroll down to free booklets and online information).

### **Top tip**

When applying for a council tax reduction, allow time for the claim to be processed. If after this time it still hasn't been processed, ask your GP surgery for a copy of the doctor's confirmation that was sent to the council. This will help you find out if the delay is from the council or the GP.

When you own your own home - joint ownership

Joint ownership means that two or more people own a property together. This often happens when a couple buys a home. They do not have to be married to share ownership. When one of the joint owners dies, the property automatically goes to the surviving owner. There is no need for the probate process. Even if the deceased owner had a will that stated their share should go to someone else. Therefore, the entire property becomes part of the survivor's estate.

This can affect care cost assessments and may have inheritance tax implications when the surviving owner dies.

Another type of joint ownership is called tenants in common. Here, two or more people own a property but hold different shares. For example, one person might own 60%, while the other owns 40%. If one of the owners dies, their share will go to whoever they name in their will.

A solicitor or the Land Registry can help with this change. The Land Registry also provides advice and guidance.

Call: 0300 006 0411 Website: www.gov.uk (search 'land registry').

#### Deprivation of assets

A person may want to transfer an asset to someone else in order to avoid it being used to pay for their care. This is called a deliberate deprivation of assets. For example, someone may transfer money into someone else's bank account, or transfer ownership of a property into someone else's name.

When deciding whether a deprivation of assets has taken place, the local authority will consider:

- The motivation for disposing of the asset.
- Whether they had a reasonable expectation of needing care and support at the time.
- Whether there was an expectation of needing to contribute to the cost of their care.

Any attempt not to include an asset in the financial assessment may be seen by the local authority as a deliberate deprivation of assets. If this happens, the local authority may assess the person as if they still owned the asset.

For more information see Age UK factsheet number 40 'deprivation of assets in social care'



Call: 0191 514 1131 Email: enquiries@ageuksunderland.org.uk Website: www.ageuk.org.uk/sunderland (search 'information and advice' and scroll down to free booklets and online information).

For personalised support contact Age UK Sunderland's Dementia Hub, The Essence Service on: 0191 522 1310





#### Banking



Banks are expected to take extra care with their vulnerable customers including people with a dementia diagnosis. The are expected to make sure peoples needs are met fairly and to spot early signs of vulnerability. They should act to prevent risk to these customers emerging or growing.

The following article 'bank accounts/investments held 'jointly' has been written by a local gentleman with lived experience of caring for a loved one with dementia.

#### Bank accounts/investments held 'jointly'

If the person with dementia has joint bank accounts or other assets held jointly, when carrying out an assessment social services can only take into account the share belonging to them. It will be assumed that the person's share is half (50%) of these joint assets, unless the person can show otherwise.

A carer may want to split the proceeds honestly and with integrity into two separate accounts. Assuming the carer has lasting power of attorney, then the account for the person with dementia will name the carer as attorney for the partner with dementia and the carer will then have a separate account in their name.

#### Tips for help with managing money

Things you can do now, to help with finances:

- To make sure bills are paid on time set up standing orders or direct debits.
- Have all your income, such as pensions and benefits paid into your bank account.
- Think about getting a chip and signature card. You only need to supply your signature rather than a personal identification number (PIN).
- Set up a third-party mandate. This gives another person access to your bank account. You can state how much access to give. An example of this would be a set amount for the weekly shop.

The information 'Tips for help with managing money' was taken from the NHS website. To read more visit: <u>www.nhs.uk</u> (search 'dementia and managing money').

### Top tip

Following a dementia diagnosis book an appointment at your bank. They can discuss any worries you have and what to do to keep you and your money safe.

After a diagnosis of dementia is made, as soon as practical, advice should be sought from the local authority to establish when:



- A financial needs assessment should be made for the person with dementia
- A carer's assessment to consider whether or not the carer can manage the task of caring or if some further intervention is required

It may be a little while before these assessments are made.

"Unfortunately, and inevitably, dementia progresses, and the following notes relate to that point in time when the person with dementia must enter residential care.

This is a horrible moment for both the person with dementia and the carer. The carer will almost certainly feel guilty, but this is a misplaced emotion. You have done your very best and have, now, to admit that you are no longer able to provide the level of care your loved one needs, so you are handing over to a professional team who are better able to give the care needed." (Local carer)

#### The financial assessment

The following information 'the financial assessment' has been written by a local gentleman with lived experience of caring for a loved one with dementia.

As dementia progresses the need for permanent residential care may increase. The local authority has a duty of support and must carry out a needs assessment to establish 'eligible needs'.

How much people pay towards this care is determined by a financial assessment. This will consider your income, savings, and assets, reviewed in a personal budget.

If this totals more than £23,250 (as of March 2025) you will be regarded as a 'selffunder'. This means people will have to pay the full cost of care home fees until your capital reduces to, or below that figure. Following this the local authority will assist with the cost of fees. The local authority will establish your assessed weekly income as follows:

- Benefits (eg attendance allowance).
- Pensions (eg state retirement pension).
- Employment pensions  $x \frac{1}{2}$  (on the assumption that the other half has been gifted to your partner).
- Tariff income where your savings and investments are valued at more than £14250 a notional 'income' of £1 is computed for every £250 above £14250 (eg savings = £15250 then national or tariff income =£4 per week i.e. £1000 divided by 250 equals £4 of notional income).

#### The financial assessment' continued

If your capital is £14,250 or less, then it must be wholly disregarded from the financial assessment.



These factors then, establish your gross weekly income. Against this amount are set expenditures which can include the expenses of utilities such as gas, electric, and water rates.

You must be left with an amount of no less than what is called a 'guaranteed minimum income'. Currently, this amount is £30.15 per week. This is subject to annual variation and is usually referred to as a personal expenses allowance.

Where you do not qualify for pension credit, guarantee credit, or savings credit then the local authority must also disregard a further £6.95 of weekly income. Your personal expense allowance is then £37.10 per week.

The purpose of the personal expense allowance is to ensure that you have money to spend on personal items. Items that are not part of personal care including toiletries, birthday gifts, newspapers & magazines and haircuts etc. Statutorily it is not to be used to cover any part of the persons care and support by the local authority

Ongoing property expenses when the person has gone into care It is important to note that Annex C, Section 46 of the Care Act 2014 Statutory Guidance states:

'There may be some circumstances where it would not be appropriate for the local authority to leave a person only with the personal expenses allowance after charges. For example:

d) Where a person's property has been disregarded the local authority should consider whether the PEA (personal expense allowance) is sufficient to enable the person to meet any resultant costs. For example, allowances should be made for fixed payments (like mortgages, rent and Council Tax), building insurance, utility costs (gas, electricity and water, including basic heating during the winter) and reasonable property maintenance costs.'

For further information visit: www.gov.uk (search care and support statutory guidance).

#### **Court of Protection**

This is administered by HM Courts & Tribunals Service. The Court of Protecti makes decisions on financial or welfare matters for people who can't make decisions for themselves due to their mental capacity.



The Court of Protection is responsible for:

- Deciding whether someone has the mental capacity to make a particular decision for themselves.
- Appointing deputies to make ongoing decisions for people who lack mental capacity
- Permitting people to make one-off decisions on behalf of someone else who lacks mental capacity.
- Handling urgent or emergency applications where a decision must be made on behalf of someone else without delay.
- Making decisions about a lasting power of attorney or enduring power of attorney and considering any objections to their registration.
- Considering applications to make statutory wills or gifts.
- Making decisions about when someone can be deprived of their liberty under the Mental Capacity Act.

Most cases are heard by district judges and a senior judge. Sometimes they can be heard by High Court judges. Cases can sometimes be transferred to a local court for hearing.

Call: 0191 205 8750 Email: <u>COPNewcastle.newcastle.countycourt@justice.gov.uk</u> Website: <u>www.gov.uk</u> (search 'court of protection forms').

For information of the fees attached to court of protection visit: <u>www.gov.uk</u> (search 'court of protection fees').

#### **Direct payments**

If Sunderland City Council assesses a person and finds they need care and support, they will offer a personal budget. This budget amount depends on the person's eligible needs at that time. The council will conduct a financial assessment. This will decide if the person must contribute towards their care costs. If a contribution is required, this amount will be deducted from the direct payment the council makes.

The council offer direct payments to allow people to buy care and support services to meet their eligible needs.

If a person or someone they care for receives help from adult services, a direct payment can be requested. This allows them to buy the care and support services to meet their eligible care needs, rather than getting services directly from them. It puts the person in control and gives more choice about how care and support is arranged and delivered. They can choose how to use the money in the direct payment. As long as it is spent on things that meet the persons personal care needs.

For more information contact Sunderland City Council:

Call: 0191 520 5551 Website: <u>www.sunderland.gov.uk</u> (search 'direct payments').

### NHS continuing healthcare



Most people have to pay something towards the care they receive. Some people with ongoing significant health needs can get their care paid for through NHS continuing healthcare.

NHS continuing healthcare is a package of care for people who are assessed as having a 'primary health need'. It's arranged and funded by the NHS.

If you receive care in your own home the NHS covers the cost of the care and support. You need to meet your assessed health and associated care needs. This includes personal care such as help with washing and getting dressed.

If you receive NHS continuing healthcare in a care home the NHS pays your care home fees.

Speak to your healthcare provider, doctor or social worker if you think you might be eligible for NHS continuing healthcare.

For more information see Age UK factsheet number 20 'NHS continuing healthcare and NHS-funded nursing care'.



#### Call: 0191 514 1131

Email: enquiries@ageuksunderland.org.uk

Website: www.ageuk.org.uk/sunderland (Search 'information and advice' and scroll down to free booklets and online information).

For personalised support contact Age UK Sunderland's Dementia Hub, the Essence Service on: 0191 522 1310.

#### Continuing healthcare - advocacy

If you need an assessment, or you're assessed as eligible for NHS continuing healthcare an advocate can make sure you have the relevant support to have your wishes, preferences and views heard.

To make a referral for yourself, friend or family, or someone you care for professionally, please contact VoiceAbility directly.

Call: 0300 303 1660 Email: <u>helpline@voiceability.org</u> Website: <u>www.voiceability.org</u> (search 'continuing healthcare advocacy').

# Thank you to our partners

This work would not have been possible without the support from our partners and local carers with lived experience of living and supporting a loved one with a dementia diagnosis. Thank you on behalf of all at Healthwatch Sunderland for your time, your passion and your commitment to producing this booklet. It is hoped it will support and improve the lives of people experiencing memory difficulties, dementia and their carers across the City of Sunderland.

#### Thank you to:

#### **Local carers**







NORTH EAST DEMENTIA CARE





Sunderland

**NHS** South Tyneside and Sunderland NHS Foundation Trust



North East and North Cumbria



Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

For the full suite of booklets which accompany this one, please visit: <u>www.healthwatchsunderland.com</u> or call us on: 0191 514 7145



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